

Medical Care Tasks among Spousal Dementia Caregivers: Links to Care-Related Sleep Disturbances

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Objective: Medical care tasks are commonly provided by spouses caring for persons living with dementia (PLWDs). These tasks reflect complex care demands that may interfere with sleep, yet their implications for caregivers' sleep outcomes are unknown. The authors evaluated the association between caregivers' medical/nursing tasks (keeping track of medications; managing tasks such as ostomy care, intravenous lines, or blood testing; giving shots/injections; and caring for skin wounds/sores) and care-related sleep disturbances. **Methods:** A retrospective analysis of cross-sectional data from the 2011 National Health and Aging Trends Study and National Study of Caregiving was conducted. Spousal caregivers and PLWDs/proxies were interviewed by telephone at home. The U.S. sample included 104 community-dwelling spousal caregivers and PLWDs. Caregivers reported on their sociodemographic and health characteristics, caregiving stressors, negative caregiving relationship quality, and sleep disturbances. PLWDs (or proxies) reported on their health conditions and sleep problems. **Results:** Caregivers who performed a higher number of medical/nursing tasks reported significantly more frequent care-related sleep disturbances, controlling for sociodemographic and health characteristics, caregiving stressors, negative caregiving relationship quality, and PLWDs' sleep problems and health conditions. Post hoc tests showed that wound care was independently associated with more frequent care-related sleep disturbances after accounting for the other medical/nursing tasks and covariates. **Conclusion:** Spousal caregivers of PLWDs who perform medical/nursing tasks may be at heightened risk for sleep disturbances and associated adverse health consequences. Interventions to promote the well-being of both care partners may benefit from directly addressing caregivers' needs and concerns about their provision of medical/nursing care. (Am J Geriatr Psychiatry 2018; ■■■:■■■-■■■)

Key Words: Dementia care, informal caregiving, medical care, medical/nursing care

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Highlights

- We examined the links between medical/nursing tasks and care-related sleep disturbances among spousal dementia caregivers drawn from a nationally representative U.S. sample.
- Over half of spousal dementia caregivers (52.3%) perform two or more medical/nursing tasks, with roughly one in five (17.6%) engaged in at least three of these care tasks.
- This study extends the literature by showing that caregivers report more frequent care-related sleep disturbances when they perform a higher number of medical/nursing tasks.
- Wound care is independently linked to more frequent care-related sleep disturbances, controlling for characteristics of the care situation and other medical/nursing tasks.
- Interventions to preserve both care partners' health and well-being may benefit from addressing the ongoing needs of spouses providing complex medical care.

INTRODUCTION

Alzheimer disease and related dementias currently affect over 5 million U.S. adults, with a projected impact on 7.1 million by 2025 and 13.8 million by 2050.¹ Along with cognitive and functional impairment, persons living with dementia (PLWDs) have high rates of chronic medical comorbidities (e.g., diabetes, heart disease) that complicate their long-term care.^{1,2} Strikingly, one-fourth (26%) of PLWDs have five or more chronic medical conditions versus only 3.8% of other Medicare beneficiaries.¹ Spouses are a primary source of support for PLWDs, with roughly two-thirds of spousal caregivers assuming responsibility for medical tasks traditionally handled by healthcare professionals.³ Medical/nursing tasks such as keeping track of medications, managing peripheral intravenous lines (IVs), giving injections, and caring for wounds require specialized skills in which many family caregivers lack training.³⁻⁶ These tasks can be difficult, stressful, and time-consuming,³⁻¹⁶ potentially interfering with caregivers' self-care. Yet little is known about their actual impact on key caregiver health behaviors.

Sleep disturbances are reported by approximately 50%–70% of individuals caring for PLWDs.¹⁷ Numerous factors contribute to caregivers' sleep disturbances, including older age, female gender, medical or psychiatric morbidity, negative caregiving relationship quality, and care-related stressors that are objective (e.g., PLWDs' nighttime awakenings) or subjective (e.g., care-

givers' emotional caregiving difficulties).¹⁷⁻²⁰ Disturbed sleep is linked to detrimental health consequences such as weight gain, cardiovascular disease, and earlier mortality.²¹⁻²³ Caregivers' sleep interruptions may also reduce the quality of care they provide and increase the PLWD's likelihood of institutionalization, underscoring the need to gain a better understanding of everyday influences on care-related sleep disturbances.¹⁷⁻¹⁹

Medical/nursing tasks may be linked to care-related sleep disturbances among spousal caregivers for at least three reasons. First, these tasks involve a considerable time commitment, limiting activities that promote healthy sleep patterns (e.g., exercise, socializing). Caregivers commonly arrange their schedules around tasks such as preparing injections or IV bags, planning and administering multiple doses of medication, and monitoring wound care.^{7,15,16} Second, during the night caregivers may need to give medication, change bandages, or check IV tubes.^{6,7,10,11,15,24} Nighttime care activities could be compounded by the PLWD's resistance or distress that further exacerbates caregivers' sleep disturbances.^{8,12,25} Third, many caregivers have no prior medical training, and concerns about the potential for serious complications might result in hypervigilance that interferes with caregivers' sleep.^{18,19} Adverse events such as drug–drug interactions, infections, and medical equipment malfunctions are a major concern for caregivers that affect up to 15% of home care recipients.^{10,13,26} The tendency to stay awake and monitor medical care could be especially strong

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